



**Involving People
Living with Dementia
Making Involvement Count**

'MAKING INVOLVEMENT COUNT'

SECTION 01 - Background

1 - INTRODUCTION

The Involving People Living with Dementia Reference group, commissioned by the South West Dementia Partnership, has recently developed 'what works' resource cards to help when engaging and consulting with people with dementia.

These resource cards have been written by people living with dementia, carers, volunteers, staff and Local Involvement Networks (LINKs) HealthWatch. Their aim is to strengthen and directly involve people with dementia as well as their families and carers.

The focus of these cards is to provide tools and techniques for staff to facilitate and support people to express their preferences, get involved in activities whilst recognising their current abilities.

This work has taken into account the general engagement, involvement and dementia specific resources already available to inform the project and understand the barriers to involving people living with dementia.

The following also offers 'food for thought' for organisations to consider different approaches when involving people living with dementia; for example at a focus group, at a conference or organising an event.

There is a large amount of reading material available for those who would like to know more. Card 4 provides some suggestions for further reading.

The Cards

The Reference group agreed to work towards the development of cards offering top tips and general guidance when involving people with dementia under the following topics:

- Background
- General principles
- Communication
- About Consultation
- Developing groups
- Recruitment and training
- Service evaluation and improvement



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2 - AIMS OF THE WORK

Using the work referenced in Cantley C. et al, (2005) Listen to Us: Involving people with dementia in planning and developing services Section 2 page 12 Dementia North, Northumbria University Newcastle upon Tyne.

People with dementia should be enabled to:

- play a full part in decisions about everyday matters and major decisions affecting their lives;
- participate in the operation and management of services, e.g. by involvement in recruitment;
- influence improvements in service operation, e.g. by prompting changes in the way in which referrals are made to specialist services;
- influence future service provision, e.g. by suggesting alternatives to traditional day care;
- have a voice in the policy-making process, e.g. by campaigning for new life-enhancing resources; and
- have a voice in the wider community, e.g. by changing attitudes to dementia through involvement in community groups.

Involvement often leads to increased self-esteem and confidence for people with dementia.

It is not easy to achieve the above which is why the Involving People with Dementia Reference group has designed these cards. Some views from the group are expressed below

"We very often go for the easy option – ask people to come to a meeting."

"We take a tokenistic approach to involvement so we can tick the box."

"We consider the family's view of the world as the default position."



The challenges

- People/organisations think they are involving people living with dementia.
- Assumptions are made that organisations know what people want.
- People are asked to fit into the way organisations work. This can be tricky.
- Identifying people living with dementia to engage with can be very difficult.
- People can sometimes feel embarrassed talking about dementia and their problems.
- Family members and friends may see the world differently from the person with dementia.
- Communication is key; the best way to engage and communicate at different stages will depend on where the person is on their journey.
- Participation requests need to fit in with people's domestic and transport arrangements.
- Location and transport arrangements for events need to be considered.
- There needs to be recognition that not everyone wants to be involved.
- The answers received will depend upon the questions you ask.
- Engagement and involvement must be worthwhile and meaningful not a tick box exercise.

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SECTION 01 - Background

3 - ACKNOWLEDGEMENTS

We are very grateful to the people with dementia, their carers and families and the various health and social care staff from NHS Trusts, social services departments and voluntary sector organisations across the South West Dementia Partnership. We are also grateful to the many people from other groups and organisations who shared their experiences with us.

We would like to acknowledge the South West Dementia Partnership for commissioning the 'Involvement Project'.

Involving People Living with Dementia Reference Group

Norman	McNamara	Person living with dementia and Alzheimer's Society volunteer
Elaine	McNamara	Partner and carer and Alzheimer's Society volunteer
Derek	Dominey	Carer and Alzheimer's Society volunteer
John	Major	Carer and Alzheimer's Society volunteer
Rachel	Canning	Person living with dementia and Alzheimer's Society volunteer
Joe	Culkin	Former carer
Edna	Colman Smith	Wife and carer
Richard	Colman Smith	Person living with dementia
Lyn	Hancock	Wife and carer
Mike	Hancock	Person living with dementia
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Alan	Ruttley	Person living with dementia
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Derek	Dodd	Alzheimer's Society
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Lynda	Hughes	Avon and Wiltshire Mental Health Partnership NHS Trust (AWP)
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Cheryl	Thomas	The Princess Royal Trust for Carers B&NES
Beth	Tovey	Community Care & Housing Dept South Gloucestershire
Lynne	Waldron	Alzheimer's Society volunteer
Toby	Williamson	Mental Health Foundation Trust
Gill	Young	Alzheimer's Society volunteer
Jane	Viner	Royal Devon and Exeter NHS Foundation Trust

Other Stakeholders

Chard Memory Cafe Somerset

Carers Group (2gether Foundation Trust Gloucestershire)

Carers Conservatory Club and Memory Support Group Laverstock Salisbury
and Elizabeth Bartlett and Dr Marie Mills

Downend Day Service Downend South Gloucestershire

Forget Me Not Centre Swindon Wiltshire

Learning and Education team Alzheimer's Society

Milestones Trust Bristol

Mind the Gap, a Salisbury Playhouse led project Wiltshire

Rememberee Group North Somerset

South Gloucestershire Local Involvement Networks (LINKs)

South West Regional Conference Alzheimer's Society Members (19th May 2011)

South West Dementia Partnership Hospital Conference Participants (5th July 2011)

The Limes Day Support Service South Gloucestershire and Joanne O' Neill

Torbay Leadership Group Devon

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4 - FURTHER READING AND RESOURCES

Useful sources of further information. This is not an exhaustive list but offers the reader a snapshot of general engagement and dementia specific resources.

Dementia Care mapping Dementia Care Mapping (DCM) is a method designed to evaluate quality of care from the perspective of the person with dementia. It is used in formal care settings such as hospitals, care homes and day care. It is based on the philosophy of person centred care, which promotes a holistic approach to care that upholds the personhood of the person with dementia

<http://www.brad.ac.uk/health/dementia/DementiaCareMapping/>

Developing forums for people with dementia **Published:** February 2007 **Authors:** Kate Jones, Lesley Prendergast **Organisation:** Dementia Services Development Centre Wales, University of Wales Bangor **Summary:** This report provides an evaluation of the Alzheimer's Society project developing forums for people with dementia by the Dementia Services Development Centre for Wales. http://www.bangor.ac.uk/imscar/dsdc/documents/Forum1_000.pdf

Innovations in Dementia Community Interest Company (based in South West) works with other organisations to make sure that people with dementia can continue to take part in their communities and have active lives.

<http://www.innovationsindementia.org.uk>

Listen to Us: Involving people with dementia in planning and developing services

Published: 2005 **Authors:** Caroline Cantley, Janet Woodhouse and Monica Smith

Organisations: Dementia North, Northumbria University **Summary:** The guide was produced by Dementia North as part of a Department of Health funded development project to explore how people with dementia can be involved in service planning and development. <http://www.scie.org.uk/publications/guides/guide17/references.asp>

My name is not dementia – People with Dementia discuss quality of life **Published:** April 2010 **Authors:** Alzheimer's Society. **Summary:** Following on from the *Dementia: out of the shadows* report, in which people with dementia spoke out about stigma and the impact that the diagnosis had on their lives, Alzheimer's Society commissioned research into quality of life in dementia. *My name is not dementia* report presents the findings of the first stage of this project.

Scottish Dementia Working Group (SDWG) is an independent group run by people with dementia. The Working Group campaigns to improve services for people with dementia and to improve attitudes towards people with dementia.

<http://www.sdwg.org.uk>

Strengthening the involvement of people with dementia toolkit **Published:** 2008 **Author:** Care Services Improvement Partnership **Summary:** This toolkit augments the section 'Involving service users and their carers' in 'Everybody's Business – a service development guide' (DH 2005)



Supplementary resource document Published: 2008 **Author:** Care Services Improvement Partnership **Summary:** This document has been compiled in the process of writing the Strengthening the involvement of people with dementia toolkit. It includes a wealth of positive practice examples
http://www.dhcarenetworks.org.uk/_library/Resources/Dementia/CSIPComment/strengthening-the-involvement-of-people-with-dementia.pdf

Supporting Derek This valuable resource pack published by the Joseph Rowntree Foundation in partnership with the University of Edinburgh, is aimed at staff supporting people with learning difficulties who develop dementia.
<http://www.jrf.org.uk/publications/supporting-derek>

Talking Mats is a communication tool designed to help people who suffer from communication disabilities or difficulties.
<http://www.talkingmats.com>

Dementia specific resources:

Alzheimer's Society for information and resources on dementia
<http://www.alzheimers.org.uk/factsheet>

Dementia UK Contact details for information and support for family carers, people with dementia and professionals. Provided by experience Admiral Nurses and available by telephone and email
<http://www.dementiauk.org>

Pictures to share - books and resources for people living with dementia
<http://picturestoshare.co.uk>

Social Care Institute for Excellence: SCIE Dementia Gateway which offers free access to a wide range of resources, focusing on key topics in dementia care, e-learning materials, and films
<http://www.scie.org.uk/dementia>

South West Dementia Partnership: This website is aimed at people working to implement the National Dementia Strategy in the South West of England. It provides information on the work of the South West Dementia Partnership, which brings together organisations from health and social care, the voluntary sector and people using dementia services to drive forward improvements.
<http://www.southwestdementiapartnership.org.uk>

The Dementia Services Development Centre The centre actively works to improve services for people with dementia and offers news, resources, videos and e-journals
http://www.dementia.stir.ac.uk/library_dementia

The Mental Health Foundation produces a range of publications, including reports, briefings and information booklets. Most of these can be downloaded free of charge from this site. <http://www.mentalhealth.org.uk>

National End of Life Care Programme NHS (2009) provides explanation and resources about advanced care planning and the different options open to people including dementia.
<http://www.endoflifecareforadults.nhs.uk>

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SECTION 02 - General Principles

5 - GENERAL ENGAGEMENT AND INVOLVEMENT PRINCIPLES

- Send letter of introduction to explain the process, consent and participation information.
- Offer choices of engagement opportunities – not just meetings. For example: one-to-one conversations, telephone calls, email or written response.
- People with dementia can act as role models. It can be motivating to see other people with dementia using their skills and abilities.
- Take time to enable people to express their views and describe their daily lives. Be aware this can be an emotional roller coaster but many wish to share their stories if this means improving someone else's experience.
- Ask one or two questions on a particular topic – do not send lengthy documents.
- Establish ground rules for meetings – see Card 11.
- Plan sessions/events – establish dates and times well in advance. Send timely and regular reminders.
- Explain reimbursement process for expenses and make this process simple.
- Be welcoming and create a friendly atmosphere. Offer refreshments. Meet and greet.
- Provide name badges to help people communicate.
- All team members need to be flexible to manage the group, e.g. not one person always making the teas.
- Plan the layout of the room – multiple tables for five to six people.
- Encourage volunteers and staff to engage with participants – some people attending may be quite isolated at home and may find it difficult to mix with others.
- Support speakers to adapt to the audience with different needs and abilities. Think about presentation tools, timings and have a flexible approach. Allow for feedback to participants at the end of the session.
- Offer information about the event to take away as a reminder.
- Say thank you and explain what you intend to do with information received. Explain what the organisation and/or service has already changed as a consequence of feedback.
- Be aware that some people will want to take the opportunity to receive information and advice.



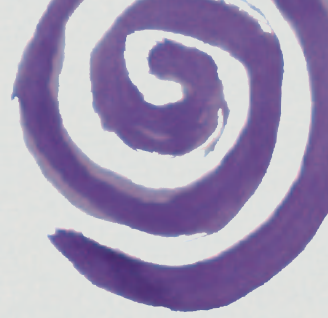
Specific to carers and family members

- Consider asking a local carers group which meets regularly to discuss the topic
- Be clear about the task, i.e. the amount of time involved, what is expected, what difference it will make.
- Consider length and timing of meetings to fit in with the caring role. Are you able to cover the costs of respite, if required?
- Consider facilitating two groups at the same venue: one for the people with dementia and one for the carers.

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SECTION 02 - General Principles

6 - INVOLVEMENT OPPORTUNITIES



There are many ways we can involve people living with dementia. We can include the individual, carers, families and friends.

- Do people need help to be involved? This will need to be in place and the person will need to be supported on the day.
- Agree a timetable of involvement with a review date.
- How are you going to involve people who are housebound, who live alone and are not using services at present?
- Provide clarity about the purpose of involvement.
- Discuss with people what interests them. Match interests with opportunities. Give people a choice. Be aware that choices present challenges. Sometimes ask questions that only require a simple 'yes' or 'no' answer.
- Don't delay in your response and action. Report on progress at all times once the person has agreed to be involved.
- How will you ensure that discussions during the event or meeting are understandable and accessible, e.g. terminology, pace and breaks?
- Get people's consent to use the information and quotes they have given to be used in different forums.
- Be clear about how people want to be known – some people are happy to be quoted by name, age and condition, others prefer to be anonymous.
- Find out how people like to communicate.
- Find out how people like to receive information.
- Find out what resources the person has in terms of skills, experience and knowledge.
- Be clear about why you wish to involve the person. This should not be a tick box exercise.
- Consider approaches – find a solution. Signpost to the appropriate organisation/department or individual.

Think of different ways of involving people, such as:

- Volunteering
- Media and campaigning
- Joining an existing group
- LINKs (Healthwatch)
- Research
- Committee/project group/focus/steering
- Mystery shopper
- Education and training
- Interviewing
- Conference speaking
- Service feedback
- Fundraising
- Peer reviews.

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SECTION 02 - General Principles

7 - INCLUSION - WHO DO YOU NEED TO INCLUDE? WHO IS SELDOM HEARD?



'Seldom heard' is a loose term used to represent individuals, groups and communities who, for varying reasons, have experienced exclusion or marginalisation from mainstream society (including access to health and social care). Some groups of people who have been particularly marginalised or excluded need extra support to ensure effective engagement.

The Social Care Institute for Excellence (SCIE) has produced a useful guide and position paper on this topic (Robson et al, 2009 SCIE 2007 www.scie.org.uk)

Seldom heard groups living with dementia include:

- Black Minority and Ethnic (BME)
- Lesbian and gay people
- People with more advanced dementia who may be living in residential care and nursing homes
- People with learning disabilities and dementia
- Prisoners
- Gypsies and travellers
- People with rarer forms of dementia, e.g. Korsakoffs, HIV-associated dementia
- People with early onset dementia (under the age of 65)
- People with no families or friends.

Unlike mental health services for people with 'functional' mental health problems, up until recently, involving people with dementia to inform types of care, treatment, and services had been relatively underdeveloped.

This can be explained for a number of reasons including:

1. Dementia being seen as an illness of old age with little attention paid to it at policy level, and a lack of investment, therefore, in developing user involvement.
2. The organic, progressive nature of dementia, combined with late or no diagnosis, meaning that it was usually quite difficult or too late to get people's views.
3. A relatively strong well-developed carers' movement who, partly because of the nature of dementia, often spoke on behalf of people with dementia, as well as in respect of their own views.

(Williamson et al (2009) Older people's mental health today: a handbook. Chapter 13 page 157 Mental Health Foundation OLM-Pavilion Brighton)

Therefore:

- You don't need to know everything – use external expertise and work collaboratively with other organisations.
- Be aware that you need to understand the range of communities and specific approaches needed.
- Community engagement is key.
- It takes time to undertake any engagement

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SECTION 02 - General Principles

7A - LEARNING DISABILITY COMMUNICATION CARD

The following is an example of what works when engaging with a person with learning disabilities and dementia:

- If at all possible, ensure you obtain as much information about the person's routine and life story prior to meeting the person.
- Ensure that the routine is maintained even if it takes a long time, this will help prevent distress at later stages.
- Sit next to the person or directly in front of them. Maintain eye contact and ensure that you have their full attention.
- Explain in short and simple sentences what is going to happen (i.e. a visit is to take place, a talk).
- The visitor should be taken in to see the person by a familiar member of staff (reassurance).
- The visitor can offer a hand to shake and must inform the person who they are and ask them where they would like them to sit.
- Staff will make a cup of tea if requested.
- The immediate environment should be quiet and free from distractions (e.g. TV/radio/other conversations).
- Staff will help people communicate and check that they are interpreting correctly.
- A familiar member of staff will explain if the person appears not to understand or digresses.
- Only one person at a time will prompt.
- Use short, simple sentences that are easy to understand.
- Do not overload with too much information/questions/choices.
- Allow time to respond and to process the information.

Milestones Trust

www.milestonetrust.org.uk has provided the above information.

Milestones Trust is a health and social care charity providing residential, nursing and community care services for people with learning disabilities, mental health needs and dementia.

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SECTION 03 - Communications

8 - WRITING STYLE, LAYOUT AND DESIGN

Writing style

- Plan what to say before you start writing.
- Present information logically, one piece of information at a time.
- Keep language simple without being patronising. You are writing for an adult audience.
- Write concisely. Remove unnecessary words.
- Keep to one subject in each sentence.
- Consider producing a draft in the first instance and get feedback.
- It is helpful to repeat some words for emphasis. For example, 'There are already **drugs** available to treat some of the symptoms of Alzheimer's disease. These **drugs** can alleviate symptoms for a limited period'. Be consistent in the words you use.
- Avoid jargon and acronyms. Explain all terms and concepts clearly. Consider including a glossary.
- Paragraphs should make sense on their own. People should not have to remember the content of the first paragraph in order to understand the second one.
- Write in an inclusive writing style, using words such as 'you' and 'we'. Do not use the passive, e.g. 'We have made changes', NOT 'Changes have been made'.
- Quotations and examples help to put the information in context.



Layout and design

- Bigger type is easier to read. Use a minimum font size of 12. People with dementia have said that this is readable. A font size of 14 is ideal.
- Split information into manageable 'chunks'. Limit the amount of information on one page.
- Use colour to distinguish between different sections of information. It also livens up information and creates a sense of optimism. Bear in mind that some colours are more difficult to distinguish than others, e.g. green. This is especially true if you use colours on top of each other.
- Avoid italics – they are more difficult to read.
- Always finish a sentence on the same page it starts on.
- Don't clutter the page. Information is easier to read if it is surrounded by blank space.
- Emphasise key information in boxes.
- Split information so that it is easy to read. The use of bullet points for example.
- Use titles and headings to separate information.
- Organise information by using one column of words on a page, instead of two or more. People with dementia have said that this is easier for the eye to follow.

Acknowledgement:

Work undertaken by Living with Dementia Programme Alzheimer's Society

ALZHEIMER'S SOCIETY GUIDANCE – Revised September 2008

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SECTION 03 - Communications

9 - HOW TO COMMUNICATE WITH SOMEONE WITH DEMENTIA

General advice

- Listen carefully to what the person has to say.
- Make sure you have their full attention before you speak.
- Pay attention to body language.
- Speak clearly.
- Think about how things appear to the person with dementia.
- Consider whether any other factors are affecting communication.
- Use physical contact, where appropriate, to reassure the person. However, do not assume that physical contact is required.
- Show respect and patience, remember it may take longer for the person to process the information and respond.

Listening skills

- Try to listen carefully to what the person is saying, and give plenty of encouragement.
- If the person has difficulty finding the right word or finishing a sentence, ask them to explain in a different way. Listen for clues.
- If you find the speech hard to understand, use what you know about the person to interpret what they might be trying to say. But always check back to see if you are right - it's infuriating to have your sentence finished incorrectly by someone else!
- If the person is feeling sad, let them express their feelings without trying to 'jolly them along'. Sometimes the best thing to do is to just listen, acknowledge and show that you care.

Attracting the person's attention

- Try to catch and hold the attention of the person before you start to communicate.
- Make sure they can see you clearly.
- Make eye contact. This will help them focus on you.
- Try to minimise competing noises, such as the radio, TV, or other people's conversation.



Using body language

- Body language is important. Agitated movements or a tense facial expression may cause upset or distress, and can make communication more difficult.
- Be calm and still while you communicate. This shows the person that you are giving them your full attention, and that you have time for them.
- Never stand over someone to communicate – it can feel intimidating. Instead, drop below their eye level. This will help the person to feel more in control of the situation.
- Standing too close to the person can also feel intimidating, so always respect personal space.
- If words fail the person, pick up cues from their body language. The expression on their face, and the way they hold themselves and move about, can give you clear signals about how they are feeling.

Other causes of communication difficulty

- It is important to bear in mind that communication can be affected by other factors in addition to dementia - for example:
- Pain, discomfort, illness or the side-effects of medication. If you suspect this might be happening, suggest that the person contacts their GP.
- Problems with sight, hearing or ill-fitting dentures. Make sure the person's glasses are the correct prescription; that their hearing aids are working properly, and that dentures fit well and are comfortable.

This information is taken from Alzheimer's Society Factsheet 500, Communicating

For information about a wide range of dementia-related topics, visit alzheimers.org.uk/factsheets

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SECTION 04 - About Consultation

10 - HOW TO GET PEOPLE AFFECTED BY DEMENTIA TO AN EVENT

- Advertise well in advance (at least six to eight weeks) with one telephone number to book places. Consider a simple poster and include a photograph of person taking the calls.
- Make advertising literature as accessible, relevant and consistent as possible (see Card 8).
- Involve people with dementia and carers in planning events to ensure that they are relevant and attractive to the intended audience.
- The venue needs to be close to bus routes, have easy access, good facilities (toilets, kitchen) and preferably in a local community venue such as a village hall, social club – not a hospital environment.
- Go to people's environments or familiar settings. Get permission to go from the organisers and those who attend, e.g. day centres and support groups. Don't sit and wait for people to come to you.
- Take account of individuals' preferences when arranging times and venues.
- Make it fun – offer lunch or combine with another activity, e.g. a visit to a local attraction. Grab people's interest. For example, organise a conference in a special venue – with a cream tea.
- Consider timing, location, length of event, refreshments.
- Consider how people will be supported to get to and attend the event, i.e. transport and expenses.
- If you have 30 people attending, consider at least 10 people facilitating and supporting at the event.
- Ask a person with dementia to speak about their experience.
- Offer independent advocates if possible/appropriate.
- Send information prior to the day so people can bring their notes with them.
- Have a clear communication plan:
 1. Brief people from health and social care teams and the voluntary sector about the event. Identify involvement champions in teams/agencies. They will be your best allies if they recognise the value of supporting people to attend.
 2. Enlist the help of people in other organisations to advertise – newspapers, shops, pharmacies, newsletters, county and local councils.



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SECTION 04 - About Consultation

11 - GROUND RULES

To enable all participants to gain maximum benefits from any engagement, learning event or meeting, the following guidelines may be useful:

- **Listen and respect** We all have a different knowledge base and life experiences as a starting point. Be aware that some of the areas covered may be sensitive for some participants.
- **Listening skills** These have to take priority in any exercise which includes patience and understanding. Maintain eye contact and listen to every answer no matter how 'off the wall' it may seem at first. This can turn out to be very relevant. Give time.
- **Support** Create a supportive environment that will allow each participant to feel comfortable asking questions; provide opportunities for participants wishing to discuss any issues in private.
- **Equality** Each participant has an equal opportunity to be involved at their own pace and to feel their views and opinions are respected and valued.
- **Time out** Each participant should feel free to take 'time out' if they feel uncomfortable at any time. Do this by being explaining this at the beginning of the session.
- **Confidentiality** All participants must respect the confidentiality of any personal information shared.
- **Be open minded** Always treat people with dementia equally and on a par with carers.
- **Differences** Recognise that people see things differently.
- **Topics of interest** Plan the sessions for discussion and include breaks every 20 minutes or so.

Acknowledgement: This information was adapted from a 'learning agreement' used by a member of Alzheimer's Society Learning and Education Team.



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SECTION 04 - About Consultation

12 - FEEDBACK



Top Tips

- Take time to enable people to express their views and describe their daily lives. It can be an emotional roller coaster to re-live experiences but many wish to share their stories if this means improving someone else's experience.
- Explain the reimbursement process for expenses.
- Send a letter of introduction to explain process, consent and participation information.
- Ask one or two questions on a particular topic – do not send lengthy documents.
- People want to know what you plan to do with the information.
- Explain how the organisation or service has changed as a consequence of the feedback.
- Provide general information on how people's views have been helpful.
- A newsletter is useful to disseminate the findings and action intended
- Say 'thank you' for their involvement.
- Make a commitment to go back and explain the outcome of their expressed views.
- People will want to 'hold you to account'.

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SECTION 05 - Developing Groups

13 - GROUP DEVELOPMENT: SOME IDEAS ON LEADERSHIP AND EMPOWERMENT

- What is the purpose of the group? Be clear about why you are meeting.
- Who is included (people with dementia and/or their carers)?
- Consider one year membership with possible renewal.
- Allow the group to form and contribute to its aim and purpose. Set ground rules (see card 11).
- Introductions are important and you should encourage involvement by all.
- An ice breaker exercise may be required to make everyone feel comfortable.
- Meetings should be led by a chairperson and/or a facilitator.
- An agenda is very useful and it is important to keep to time.
- Items for discussion can vary from offering views on proposals for services from the local Care Trust or considering evaluation forms for use in local Memory Cafés.
- Consider the different forms of communication required.
- Provide notes as a record of the meeting. These should be reviewed at each meeting.





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SECTION 06 - Recruitment and Training

14 - INVOLVING A PERSON LIVING WITH DEMENTIA IN INTERVIEW PROCESSES

People with dementia and their carers need to be supported at every step during this process.

Preparation:

- Discuss with people how they would like to be involved.
- Support people to write the questions they would like to ask.
- Ensure all information is sent by post and in a format that is acceptable (This gives the person time to read the information and ask questions prior to the day)

Day of interviews:

- Have discussions in advance to help people with dementia and carers think about how they can 'evidence' their viewpoints in relation to candidates rather than just giving 'gut instinct'.
- Practice the interview scenario in advance so they know what it will be like on the day.
- Have someone to take notes on their behalf so they can be reminded of what was said when you are having post interview discussions.
- Be clear of their role – are they giving a personal experience perspective or are they full members of the interview panel? How much weight are you giving to their viewpoint when making decisions?
- Have enough breaks in proceedings to discuss candidates properly before moving onto next, or else they will all start to merge into one.
- Agree some 'distinguishing features' as you discuss the candidates – so you can use this short hand to remind people later on in the day about earlier candidates.
- Don't interview too many people. It will be really difficult for people to keep focused on later candidates if they are getting tired.

Notes:

It might be an idea for people with dementia and carers to have a separate person to discuss their thoughts with, away from the other interview panel members.

Acknowledgement: Innovations in Dementia Community Interest Company and GP lead interviews South West Dementia Partnership December 2010

Real life example

A person living with temporal lobe dementia, aged 64 and diagnosed 18 months ago, reflected on his experience. He had no experience of interviewing before and never had an interview during his working life.

His thoughts:

“The manager asked me to consider being involved (in interviewing) and gave me two weeks to consider the opportunity.”

“Really enjoyed the experience and really pleased to be involved.”

Things to consider in the future:

“Consider the opportunity to have two processes for interviewing other people in future. Have a formal process like I was involved in and another one to meet everyone at the service. This way you will get to know the person in both situations.”

Manager of service’s thoughts:

“I do feel that all of us benefited from the experience – for me it made me take some time to think about how the person might feel, and how I could best support him emotionally and practically. The person was definitely contributing to the scoring of each question and on several occasions did not agree with the panel so he wasn’t being ‘led’ in his decision making.”

“I admit I was nervous about how it would all work out – but actually I needn’t have worried – and indeed, it has spurred me on to do more, this is the way I will work in the future.”

'MAKING INVOLVEMENT COUNT'

SECTION 06 - Recruitment and Training

15 - GUIDING A PERSON WITH DEMENTIA THROUGH A PRESENTATION AT A CONFERENCE, LECTURE OR EVENT



You may act as the facilitator or interviewer to support the person

- Be clear why you are asking the person to participate and how you will support them throughout the process. Check that they are willing to participate.
- Understand your role (for example as the interviewer) in the whole process.
- Explain the event, the process and how the presentation will be undertaken. Remind the person about the event in the lead up.
- Does the person accept their diagnosis and condition?
- Give the interviewer and person with dementia an opportunity to prepare: outline the topic and discuss the options that might be considered. Agree some key questions.
- Agree whether the person will be willing to take questions from the floor? However, be prepared for them to change their mind on the day and be prepared to give them support with unexpected/difficult questions.
- Agree on the format of the interview beforehand and use suitable reminders/ prompts before and on the day.
- Consider the comfort of the person: is it light enough, too bright? The person interviewing may be sat in front of a window or masked by shadows.
- Is there noise which could be eliminated?
- Consider the time limit and concentration levels (maximum of 20 minutes may be sufficient).
- If possible the interviewer should meet regularly with the person to gain relevant history and to build rapport and trust.
- Be prepared for the person with dementia to go off course during the interview and have a strategy for managing this.

- Be prepared to support the person if they become agitated or nervous.
- Take care not to influence the person to make statements which meet the desired outcome of the event.
- Ensure the person is supported after the event.
- Consider providing feedback to the person for their contribution.
- Remind the person that they have the right to change their mind about participating.
- Let the person know that the audience may be moved by their contribution.



'MAKING INVOLVEMENT COUNT'

SECTION 07 - Service Evaluation and Improvement

16 - DIFFERENT TOOLS AND TECHNIQUES

General:

- Use the cards in this pack as reference.
- Take time to prepare and plan the approach. Recognise that evaluation can take some months if you are going to be inclusive and involve staff, individuals, carers and volunteers.
- Apply good ethical principles in your work, including getting full, informed consent.
- Provide an invitation letter, participation information sheet and contact telephone details when undertaking the evaluation.
- Be transparent – how do you intend to use the feedback collected?
- How are you going to inform participants of the outcome?
- You should also think about your own support needs, especially if this approach isn't a situation you have previously been in.
- Resources such as pictures, word cards and poetry provide helpful stimulation conversations and interactions for some people.
- Consider different tools for different audiences.
- Be creative in the design of the evaluation approach.
- Involving and engaging people with visual and hearing impairment requires a specific approach.
- Offer people the opportunity to be involved even if they cannot attend the event. (For example arrange a telephone appointment or ask them to feed back in the way they would like to).
- Respect that people may not want to provide you with feedback.
- Consider an action plan as a consequence of the feedback.

Examples of open questions

- What is working well?
- What is not working well?
- What changes would you like to see?
- Is there anything else you would like to tell us?
- If we had the opportunity to ask the service/team to stop doing something/do something different/do something more, what would it be?
- How does your day make you feel?
- What activities do you enjoy the most?
- What difference has it made to you – can you share some examples?
- Keep it simple – one question may lead to a discussion about the topic.

Different tools and techniques could include:

- One-to-one conversations
- Telephone interviews
- Talking mats (some people with dementia may have difficulties with conversational interviews or questionnaires. You can show picture cards with images that represent different aspects of quality of life and asked to place it on a mat according to whether it is 'very important' 'quite important' or 'not important'. <http://www.talkingmats.com>)
- Dementia Care Mapping (DCM) – a method designed to evaluate quality of care from the perspective of the person with dementia. It is used in formal care settings such as hospitals, care homes and day care. It is based on the philosophy of person centred care, which promotes a holistic approach to care that upholds the personhood of the person with dementia <http://www.brad.ac.uk/health/dementia/DementiaCareMapping/>
- Recording and transcribing
- Using case studies
- Questionnaires
- Focus groups
- Email responses
- Pictures and poetry
- Experienced based design (EBD) – a way of bringing patients and staff together to share the role of improving care and re-designing services. http://www.institute.nhs.uk/quality_and_value/introduction/experience_based_design.html



'MAKING INVOLVEMENT COUNT'

SECTION 07 - Service Evaluation and Improvement

17 - SOCIAL INTERACTION - ACTIVITIES AND MEANINGFUL OCCUPATION

Tips from people with dementia:

- Attempt to move into my reality – be where I am.
- Who else knows me well? Involve them.
- Acknowledge and deal with my feelings even if they do not feel real to you.
- Take the time to find out about my interests, what I have done in my life and how I like to be involved.
- Find out the best way to communicate with me.
- When is the best time to talk to me? This has to take into consideration my daily routine and 'good' times of day for me.
- My preferred place. Where is it best? For example, I chat best when I am making a cup of tea or perhaps I need to be in a quiet environment. Find out!
- Don't assume I like knitting, bingo or colouring in a book!
- I need to be aware of reality but don't keep reminding me. Link me with news or people of the day.
- I like to do something that's worthwhile and has meaning.
- I need a role.
- I need to feel useful and able.
- I am able to: clear up the dishes, clear out a draw, make the beds, go for a walk and talk, but may need you to prompt and guide.

Many people living with dementia want to continue enjoying the things they have always done and can still do. Or they may want to try new things and develop new skills. People do not want to be excluded because they have dementia. It is important that people are still presented with choices but presented with them one at a time.